

The New York AAPI Special Needs Survey

纽约AAPI特殊需要家庭调查问卷

Families Advocating for Individual Rights

家庭倡导个人权利

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What is FAIR?

Families Advocating for Individual Rights (FAIR) is a parent-led program supported by and working in collaboration with the Chinese-American Planning Council (CPC) that aims to empower and advocate for Asian American and Pacific Islander (AAPI) individuals living with developmental disabilities (DD). We strive to foster an inclusive community, provide support, and promote awareness to ensure that AAPI individuals with developmental disabilities have access to the resources and opportunities they need to thrive.

Chinese-American Planning Council:

CPC is the nation's largest Asian American social services organization. Founded in 1965, CPC promotes the social and economic empowerment of Chinese American, immigrant, and low-income communities in New York City by ensuring they have equitable access to the resources and opportunities needed to thrive. CPC served 80,000 community members last year through 50 high-quality programs in 37 locations supporting education, family support, and community empowerment.

New York AAPI Special Needs Survey

AAPIs are the fastest growing racial group in New York City, primarily due to an influx of immigrants over the past several decades. This diverse immigrant population represents AAPIs from more than 30 different ethnic groups who speak more than 50 languages. In New York City, nearly half of the AAPI immigrant population is Chinese. 52% of all NYC AAPI immigrants live in Queens (Mayor's Office of Immigrant Affairs, 2021).

AAPIs were recently recognized by New York State as an underserved population amongst those with developmental disabilities (OPWDD, 2022). It is well-known among researchers that communitywide data about New York AAPI residents living with DD is insufficient and difficult to find.

The *New York AAPI Special Needs Survey's* goal was to address this lack of information by collecting data on challenges faced by AAPIs living with DD to better support the needs of the community. The project's unique participatory action research design ensured a core group of family members of individuals living with DD and community stakeholders provided insights and critical guidance to the survey's content and overall direction. The framework was intended to empower families of individuals with DD priorities and to reflect their lived experience.

The survey was created by FAIR members, with support from community stakeholders and CPC staff, and benefitted from the expertise of Dr. Xinwei Zhang who collaborated with families to create the survey. Conducted online through Qualtrics, the survey was offered in five different languages (English, Simplified Chinese, Traditional Chinese, Nepali, Spanish). FAIR members promoted the survey through social media and at events serving the DD community as well as

through their own online networks. CPC supported efforts by promoting the survey widely among AAPI-serving non-profit community groups, through web and social media, and with help from city and state representatives.

Open from August 25th to November 6th, 2023, the survey collected 227 responses of caregivers and/or individuals with DD. Most caregiver respondents were limited-English-proficient Asian community members identifying as Chinese. A majority of caregiver respondents (63.9%) lived in Queens County. A significant number (76.4%) of individuals living with DD were under the age of 21 and diagnosed with autism spectrum disorder (66.2%). Nearly half of individuals with DD surveyed live in a household with annual incomes below \$35,000, with only 16% of their caregivers employed on a full-time basis. While most individuals with DD surveyed were school-aged children (57%), only half of them are receiving school-based special education services.

Key Findings

AAPI community members caring for someone with DD or those living with DD face myriad language and cultural barriers that can be compounded by the complexity of DD support service processes, resulting in a lack of sufficient support for special needs families. Nearly half (48.9%) of the individuals with DD represented in the survey reported not receiving needed services. These individuals reported needing, but not receiving, essential services such as homecare (67.4%), transportation support (60.5%), assistance provided by the Office for People with Developmental Disabilities (OPWDD) (60.5%), and public benefits e.g., SNAP, SSI, SSDI, WIC (58.1%).

When asked why they are not receiving needed services, the top four reported barriers were **1) lack of information, 2) complexity of application processes, 3) extensive wait times, and 4) language barriers.**

- 1) Lack of information (62.8%) described uncertainty on where to access resources/services and qualification criteria. Only 14.5% of the 227 survey respondents said they knew where to find the information they needed.
- 2) Complexity of application process (60.5%) referred to the complex and time-consuming nature of applying for services. As a Chinese caregiver of an individual with Cerebral Palsy described in the survey, “Every application takes an extremely long time and the waiting period is indefinite.” Another caregiver of an individual with autism spectrum disorder noted, “[Knowing] what services a child with DD (ie: ASD) should be getting from the city or out of pocket is not clear. Whether you are a citizen or new American [the process] can be confusing and at times overwhelming.”
- 3) Extensive wait times (32.6%) described that many community members must wait on hold for an extensive period when trying to receive or apply for services and also that families experienced situations where service providers did not follow up. One Chinese

caregiver of an individual who was diagnosed with autism spectrum disorder two years ago reported, “We applied for OPWDD last year but still haven't received any response.”

- 4) Community members reported that they faced language barriers (32.6%) including not receiving the language support they needed to navigate service processes. With nearly 90% of caregivers and 60% of individuals with DD having limited English proficiency, 57.3% of the 227 survey respondents reported needing a translator to help them communicate with service providers.

Recommendations

Survey findings underscore the urgent need to enhance accessibility of service information, addressing the complexity of the application process, extensive wait times, and language barriers. The complicated nature of applying for and maintaining services underscores the need for more service navigation assistance to make programs more inclusive and accessible. To achieve this we, the FAIR member parents/stakeholders, recommend the following:

1. Develop user-friendly and transparent communication tools to increase access to services such as:
 - a. Standardizing clear and consistent information across existing platforms detailing city and state services for families, with a focus on user-friendly explanations and language accessibility
 - b. Offering community-based workshops, information sessions, and outreach programs tailored to the linguistic needs of families, ensuring content is up-to-date and accessible
 - c. Creating a road map and instructions in plain language for families beginning application and evaluation processes
 - d. Creating an application tracker to increase transparency of application status for families
2. Streamline intake processes, increase resource allocation for those who are Limited English Proficient (LEP) to increase language accessibility, improve coordination among service providers, and enhance staff training to reduce extensive wait times for families to access services
3. Establish a task force, that involves community input, to track and provide feedback on accessibility of service information, focusing on the use of clear everyday language and language accessibility
4. Mandate an annual report, put together by the above task force, that assesses the quality of service, translation, and interpretation
5. Incentivizing contracts to community-based organizations (CBOs) that have a track record of cultural and linguistic competent services to help community members navigate services